Chapter 2
Ethical Governance and Ethical Tools

Ethically sensitive decision making is needed both with regard to general policies on human enhancement and with regard to specific enhancement applications. Science, technology and innovation policies may, on the one hand, be developed to support or steer HE technology trajectories in certain directions. This requires societal deliberation regarding the kind of innovation we, as a society, want to encourage. For this purpose, it could be important to consider, for instance, whether the technology inherently contributes to or challenges our concepts of agency, autonomy or personhood. This is the kind of deliberation that Stirling (2008) presents as "opening up" reflection, questioning both the purposes of the innovations and considering alternative ways of achieving these purposes (including non-technological means) (Rip and te Kulve 2008). An informative approach to deliberating the overall ethical and philosophical questions (the Socratic Health Technology Assessment) has been developed by Hofmann (2016), Hofmann et al. (2016) based on a review of Health Technology Assessment approaches.[1]

As we argue in Chap. 1, there is, on the other hand, also a need for ethical assessment of specific applications. This kind of ethical assessment will often have a regulatory or decision-making focus. Risk assessments are commonly applied in the area of pharmaceuticals or medical inventions, but sometimes there may also be a desire to ethically assess specific applications.[2] For instance, potential consumers or users (such as socially responsible doctors) may want to ethically assess HE applications before they make purchasing-decisions; producers may want to ensure that their products are ethically acceptable; or policy makers may want an ethical

[1]Hofmann's work was somewhat similar to the work presented in this book, but took as a starting point the Health Technology Assessment tradition, while we in this book specifically consider the tradition of practical ethical frameworks in emerging technologies. The two strands of work also target different decision making levels.

[2]In Norwegian gene technology legislation such application focused ethical assessments are in fact required for all genetically modified organisms (GMOs) as a supplement to scientific risk assessment.

E.-M. Forsberg et al., *Evaluating Ethical Frameworks for the Assessment of Human Cognitive Enhancement Applications*, SpringerBriefs in Ethics,
DOI 10.1007/978-3-319-53823-5_2

assessment when considering policy interventions. This is the kind of deliberation that Stirling (2008) describes as "closing down". This is the decision making level targeted in this book, where no framework yet has been proposed in the field of HE.[3]

These opening up and closing down levels will be interrelated, even if the two different kinds of deliberation have different characteristics. Societal deliberation will inform the frameworks that guide application oriented decision making, and vice versa, and both may inform policy, albeit in different ways. The philosophical debate between the transhumanists and the bioconservatives may be most valuable for informing more open deliberation of HE technologies because they raise general philosophical questions. However, the strongly framed philosophical stances are not apt as a basis for regulatory or decision oriented policy-making, as these positions are hard to reconcile with the current paradigm of evidence-based policy making.[4]

2.1 Ethical Tools as Vehicles for Practical, Ethical Dialogue

Beekman and Brom (2007) suggest in the biotechnology context the use of "practical instruments that can be used (tools) in order to support debates and deliberative structures for a systematic engagement with ethical issues" (2007, 4).[5] Beekman and Brom refer to a European project, Ethical Biotechnology Assessment Tools (the Ethical Bio-TA Tools project), which identified and reviewed a series of ethical tools or frameworks. The Ethical Bio-TA Tools project identified three major types of tools: Decision-making tools, public consultation and involvement tools and food chain value communication tools (see Table 2.1).

Decision-making tools were defined as tools that would aid ethical decision- and policy-making, in other words, assist in closing down on decisions. Such tools should not be seen as mechanical decision-processes, but rather as "something that can help you use your judgement" (Seedhouse 2009, 107). *Public consultation* tools designated *process* tools with procedures to elicit information on facts and values from experts, stakeholders or lay people, as well as procedures to deliberate on these. Examples are citizen's panels, Delphi processes, stakeholder workshops and consensus conferences (see Fixdal 2003; Rowe and Frewer 2000). These public consultation tools mainly have the purpose of opening up debates. *Food chain*

[3]Indeed, from Forsberg et al. (2014, see Table 5.1) it appears that this is a general gap in the ethical assessment of emerging technologies.

[4]It should be noted that proposents of these approaches present a rich variety of ethical arguments, not only the abstract, philosophical ones that seem to lead to deadlocks. These more concrete arguments will be important to consider in any ethical discussion of HCE.

[5]In this book, the terms "tools" and "frameworks" will be used interchangeably.

Table 2.1 List of frameworks discussed in the ethical bio TA tools project

Decision-making framework
Casuistry
COGEM framework
Critical systems heuristics
Delphi method
Discourse ethics
Ethical codes/guidelines
Ethical matrix
Multi-criteria mapping
Precautionary principle
Principle based ethics
Risk analysis
Stakeholder analysis
Value-tree analysis
Public consultation and involvement
Citizen's forum
Consensus conference
Focus group
Future workshop
Public hearing
Public forum
Referendum
Scenario workshop
Technology Delphi studies/technology foresight
Food chain value communication
Benchmarking
Ethical accounting
Ethical audits
Ethical codes
ISO 9000
Normative standards
Stakeholder dialogue
Stepwise dilemma-solving
Total quality management
Value clarification
Weston's toolbox

value communication tools were especially targeted to the needs of stakeholders in an industrial context.

We believe in general that the ethical discussion in HCE can benefit from systematic reflection on ethical tools, in a manner similar to the biotechnology context. We can therefore learn from the Ethical Bio TA Tools project. More specifically, we argue that the decision making tools are generally appropriate for application oriented

decision/policy making needs, which is our focus in this book. Public consultation tools are especially important for societal deliberation of technology policy in general. Finally, food chain value communication tools may be relevant as tools for the (future) HCE industrial value chains, but will not be addressed here.

2.2 Quality in Practical Ethics

For all of these kinds of ethical assessment tools, a crucial concern is to ensure their quality. An ethical assessment tool is of no value if it is of low quality. Ethical assessments should not be biased or misleading, or refer to non-relevant issues. Such concerns with quality have led researchers to study what characterises good ethical assessments. In particular there has been a focus on how ethical tools may help to ensure high quality ethical assessment. In the Ethical Bio-TA Tools project, the term "soundness" was used to indicate a concern for methodological quality of ethical frameworks:

> an ethical framework is ethically sound *iff* [if and only if] its application produces understanding of ethically relevant considerations in such a way that within a given body of knowledge and on condition of its competent use no further considerations would decisively alter the normative conclusions drawn from the framework by the users (Kaiser et al. 2004, 26).

Ethical soundness was operationalised as:

1. Inclusion of values at stake;
2. Transparency;
3. Multiplicity of viewpoints;
4. Exposition of case relevant ethically relevant aspects;
5. Inclusion of ethically relevant arguments (Kaiser et al. 2004, 27).

Moula and Sandin (2015) have some objections to Kaiser et al.'s approach, but similarly conclude that all high quality ethical frameworks should be *comprehensive*, i.e. consider a broad range of ethically relevant aspects. They also stress the need for frameworks to be *user-friendly*. For decision guiding tools they also argue that the criteria of transparency, guiding users toward a decision and justification of the decision-supporting mechanism as important.

In bioethics there has similarly recently been an extensive reflection on what makes an ethical analysis or approach good. Even if this reflection has been more related to what good scholarly analysis is rather than what characterises a good, practical ethical tool, it is useful to consider this discourse.

One group of quality criteria addresses the impact of ethical approaches. Rothman (1991) and Caplan (2015) propose that a good approach is one that alters moral authority. Stevens (2003) and Koch (2012) suggests that an ethical approach is good if it sells bioethics to the establishment and generates funding. Fox (2008) and Evans (2011) argue that a good approach provides apparent objective expertise

in identifying and addressing ethical issues. Sheehan and Dunn (2013) focus on the approach's ability to influence policy, while Chan (2015) suggests that it should forge workable (policy) decisions by responding to moral disagreement and generating new understandings. Harris (2015) suggests more generally that an ethical approach should make the world a better place.

Sugarman and Sulmasy (2010) suggest achievement-based criteria for goodness. A good approach or framework expands knowledge, exposes hidden assumptions, challenges prevailing convictions, makes rigorous arguments, enriches understanding, and illuminates contentious issues in new ways (Sugarman and Sulmasy 2010). This seems to be a stance very much consistent with Kaiser et al. (2004) and also with Dunne (2012) who focuses on a framework's ability to develop justifiable and practically useful arguments.

Good frameworks may also be characterized by various process characteristics. Bowman claims that medical ethics should actively seek "perspectives and contributions from people other than academics and clinicians" and empower to action (Bowman 2015, p. 61). Montgomery claims that bioethics should focus "more on who does things, how and why they do them, than in what they study and what they conclude." (Montgomery 2016, p. 20). That is, the quality of bioethics depends on the legitimacy of its institutions to operate in the public sphere (depending on how their members are selected; the nature of the authority that they exercise; the processes by which positions are reached; the efficiency, proportionality and effectiveness of the accountability mechanisms that can be invoked), on the forms of institutionalisation of bioethics, as well as on the forms of bioethics governance; such as opinions, reports, guidelines or consensus statements.

Eckenwiler and Cohn (2009) and Hedgecoe (2004) have proposed criteria related to the tasks of the frameworks, such as being social critics or watchdogs, and challenging injustice.

Rhodes is one of the scholars who provides the most specific and operational criteria. She argues that a good framework in ethics "is coherent, illuminating, accurate, reasonable, consistent, informed, and measured" (Rhodes 2015). By this she means that the analysis should be in coherence with existing systems of norms and values in practice, clarify conceptual issues and solve real problems, refrain from simplistic understandings and unreasonable adherence to specific rules or principles, be informed by a broad range of sources, and avoid exaggerations.

Thus, most of the criteria found in bioethics are general criteria related to its process, its tasks (critical or supportive), its overall goal, or its achievements or impacts.

2.3 Criteria for Good Ethical Tools

As outlined above, in this book, we are interested in tools that help us go beyond the philosophical debates between transhumanists and bioconservatives in order to assist practical decision makers in concrete ethical deliberation and decision

making. In this sense we would look for achievement-based tools that aim to increase *comprehensiveness* and broad inclusion of values. This is in line with Kaiser et al. (2004), Moula and Sandin (2015), Sugarman and Sulmasy (2010), Dunne (2012) and Rhodes (2015). Moreover, we assume that these practical decision makers are seldom learned philosophers and we therefore attach great importance to the criterion of *user-friendliness*, which is also highlighted by Moula and Sandin (2015). In terms of impact, we would agree with Sheehan and Dunn (2013) and Chan (2015) that a framework should forge workable decisions; indeed, finding out how to do this in a sound way is the point of departure in this book. However, in a pluralist society we do not think that a framework that is designed to produce a certain impact, such as 'selling' HCE or warning against HCE, is an option for decision makers with a public mandate. Rather, for such decision makers the capacity of the framework to make value judgements *transparent* would be more important. This holds especially for public decision makers. In our view, this transparency should include specifically show how users are guided toward a decision and on what basis they reach it.[6] One might perhaps argue that the importance of user-friendliness is already implied in the notion of a 'tool'. A tool must somehow be seen as useful by a user in a certain setting. Since we target a range of users, the tool must have a certain broader user-friendliness.

Moreover, it is hard to conceive that a broadly usable framework generally should aim at changing moral authority (Rothman 1991; Caplan 2015); it will depend on the situation who has moral authority and whether this authority should be changed.

It is not so important in the decision context targeted here to assess the way the governance structure is organised (for instance, the involvement of the lay people in ethics committees). We are here interested in decision making tools that can be used by a variety of actors, and not in a more specific governance setting. We are not so interested in process criteria (Bowman 2015; Montgomery 2016) or process tools (such as consensus conferences) because we target a variety of decision makers and it would be too much to expect, for instance of a small company wanting to develop sensor based HCE, to organise such a process. Such tools are generally used by professional assessment institutions, such as technology assessment (TA) boards. Here we are rather interested in tools that help the user to identify and analyse ethical issues through the provision of information regarding relevant values or principles. Tools with an explicit ethical content may be used by anyone and should help public or private decision makers to communicate their views and judgements. In this situation, epistemological criteria, such as those proposed by Rhodes (2015), Kaiser et al. (2004) and Moula and Sandin (2015) would be more useful. In sum, from reviewing the proposed criteria we seem to end up with comprehensiveness, transparency and user-friendliness as the most relevant criteria.

[6]In other words, we combine Moula and Sandin's three specific criteria for decision-guiding tools into the transparency criterio.

It should be clear that there is a need for sound ethical frameworks for both levels of analysis indicated above; for both open ethical deliberation on the technologies policies and developments and ethical assessment that may aid more practical decision- and policy making; and the quality criteria for frameworks at the two levels may be quite similar.[7] However, in this book we focus on ethical frameworks for assessment of specific applications (or generic groups of applications) with a clear decision making focus, for instance related to decisions as to whether or not to buy, market or to allow marketing of such applications. In such a situation, we will take as a starting point the need for frameworks to facilitate transparent ethical decision making in practice and to be usable for non-philosophers. Moreover, according to the soundness definition given above, this framework needs to be able to incorporate the values at stake, a multiplicity of viewpoints, exposition of case relevant ethically relevant aspects and inclusion of ethically relevant arguments (i.e. what we can call comprehensiveness). Regarding the latter two aspects, the framework should provide directions for further fact finding that will clarify the ethical aspects.

The aim of this book is thus to make a reasoned argument for a sound ethical approach that might be used by decision makers to ethically assess HCE in a comprehensive, transparent and user-friendly way. We will do this by systematically considering existing frameworks from adjacent technology fields and determining their fit for HCE related issues. In order to do this we need first to outline HCE related ethical issues, as these concerns must be addressable in the frameworks. This will first be done by presenting two generic cases of HCE applications and their related ethical issues. After presenting these issues we will identify different candidate frameworks for ethical assessment in HCE and evaluate the ways in which these frameworks are able to transparently address the ethical issues while being user-friendly. We will then be in a position to make recommendations about ethical assessment frameworks that will aid users to draw conclusions in a sound way.

In the following section, we will offer a description of the two main application areas of focus here, i.e. pharmaceutical enhancers and non-invasive brain stimulation techniques. These two cases have been chosen because they are already available on the market and will be increasingly available, as we have already described in the introduction. They have also been discussed in the literature. We will list and briefly describe the general ethical issues that are discussed in relation to the two cases. We focus specifically on non-therapeutic applications and refer only to therapeutic applications where ethical issues touch on both kinds of application or where they are mentioned in accounts about non-therapeutic applications. It should be noted that the ethical issues identified for these two cases cover most of the issues that are relevant for HCE applications so the validity of the argument in this book extend beyond these two cases.

[7] As indicated in Hofmann (2016).

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http://www.springer.com/978-3-319-53822-8

Evaluating Ethical Frameworks for the Assessment of Human Cognitive Enhancement Applications

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2017, IX, 62 p., Softcover
ISBN: 978-3-319-53822-8